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What do patients want from medical research?

If you do a public opinion poll on priorities for medical research, top of the list will be cures—for cancer, heart disease, blindness. But ask patients and their relatives and you hear a different story. Many want research on better ways to live with ill-health, and some will declare that clinical trials based on a narrow medical model of disease have neglected their prime concerns. By chance, I found myself at a gathering to discuss the incorporation of consumer perspectives in the work of the Cochrane Collaboration, which conducts systematic reviews of published research. In one presentation we heard about a consultation where members of the Cochrane Subfertility Group, mainly doctors, had invited nurses, counsellers, purchasers, and people from patients' organizations to talk (with the aid of a 'facilitator', S Oliver) about key aspects of infertility research. As originally defined, the population under discussion had consisted of 'infertile couples'; at the close the definition had been revised to 'couples wanting a baby and seeking help'. At the beginning the interventions were 'drug treatment and surgery'; at the end they were 'information giving, listening, peer support, counselling, drug treatments, surgery, and laboratory services'. And the outcomes, originally 'pregnancy, secondary/surrogate measures', changed to 'baby, pregnancy, anxiety, stress, problem solved, relationships'.

Researchers have so far been reluctant to involve consumers in this way; and, even when consumers have been consulted on the design and end-points of trials, there have been barriers of language and culture. Some consumer representatives even express the fear that, if they lend a hand, they may be accused of joining 'the enemy'. Researchers the enemy: has it come to that? To see what substance there was in the complaints I looked back at the clinical trials published in *The Lancet* during the past year to see how they might have impressed the consumer seeking ways to better personal care. Few papers, alas, would have brought much comfort to the individual patient—even those which created a big stir in the daily press. For example, in population terms a small gain in 5-year breast cancer survival can have great numerical impact, but have we given sufficient attention to the down-side—for example, the repercussions of premature menopause? Some articulate patients already declare that we have not, and that existing indices of 'quality of life' are no solution.

Perhaps one reason why the term 'evidence-based medicine' generates strong antibodies is that the evidence we possess is so incomplete; and a narrow medical rationalism may be one reason for the drift from conventional medicine. The latest information on this phenomenon comes from South Australia, where a population survey showed that 20% of adults had visited an alternative practitioner in the past year—most commonly a chiropractor[1]. The typical user was not chronically ill but an optimistic young person who took regular exercise. The economic implications are not trivial: the calculated costs of alternative medicines in Australia were nearly double those of all prescribed pharmaceutical drugs. Similar trends are seen in other developed countries. In the USA expenditure on alternative medicines is reckoned at nearly 14 billion dollars a year. In the UK, more than half the health authorities are now purchasing alternative or complementary medicine.

What lessons can we learn for the growing popularity of alternative therapies? One proposal is that we expose the techniques of alternative medicine to the rigours of controlled trials, in the expectation that many will be proved ineffective or even harmful; the best could then be absorbed into conventional practice. Against this is the argument that there is more to alternative medicine than the techniques themselves. Some systems are akin to religions, having benefits that do not lend themselves to scientific reductionism: 'In a person who uses alternative therapies the illness experience can become a vehicle for an enlargement of the sense of self just when illness (or the threat of illness)

is raising the spectre of human frailty and isolation'[2]. One thing is clear: when assessing treatments, whether conventional or alternative, clinician-scientists need to broaden their perspectives. The most important ingredient in alternative medicine, severely rationed in conventional practice, may even be time—the time to listen and connect. When a new community hospital was being built last year in a state of New England, the planners declared that the examination rooms should have no chairs for the doctors; chairs might encourage them to sit down, chat, and thus become less cost-effective. The planners, I suspect, could not have been more wrong.

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Editor

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